

# Game Changers

## Cathy McMorris Rodgers on the Congressional Down Syndrome Caucus

By Tami Nantz

**Rep. Cathy McMorris Rodgers (R-WA) introduced two pieces of legislation last month that would guarantee a huge step forward for individuals with special needs, specifically those with Down syndrome. According to her web site, “research for a treatment and cure [for Down syndrome] has lagged behind other medical conditions.” *H.R. 2695: The Trisomy 21 Centers of Excellence Act of 2011* and *H.R. 2696: The Trisomy 21 Research Resource Act of 2011*, if passed, would “ensure that Down syndrome research remains on par with the research infrastructure of other diseases.”**

McMorris Rodgers is no stranger to the special needs community. When she and her husband Brian welcomed their son Cole McMorris Rodgers into the world in 2007, little did they know how deeply they would be affected by the journey on which they were about to embark. Within a few days of his birth, they received confirmation that their new little bundle of joy had Trisomy 21, also known as Down syndrome. “Hearing the test results was the most difficult,” she told Northwest Women’s Magazine in 2008. “Every parent has hopes and dreams for their child, Down syndrome is not on the list. It is not what we expected, yet we have embraced Cole as the special gift from God that he is. We are developing new dreams for our son and look forward to seeing him reach his potential.”

As I sat down to talk with the Congresswoman about women and the GOP last month (see the July issue of Smart Girl Nation), I couldn’t help but first ask about what has undoubtedly become one of the most important issues of both her personal and political life--her efforts on behalf of those with disabilities. It became instantly clear that her son has had an enormous impact on her life. “Cole...wow,” she began with the look of a mother completely in love. “Having a child with special needs is not what anyone ever imagines is going to be a part of her life, but in so many ways, I feel like he’s opened my eyes anew to the value of each person, and what he or she has to offer. I’m more passionate about that than ever, because of Cole. I don’t think he has any clue as to the impact he’s had on my life.”

And impact her, he has. In 2008, Congresswoman McMorris Rodgers founded the Congressional Down Syndrome Caucus, and joined forces as co-chair alongside Representatives Pete Sessions (R-TX), who has a son with Down Syndrome, Patrick Kennedy (D-RI) and Eleanor Holmes Norton (D-DC), who also has a daughter with Down syndrome. The goal in forming the bipartisan Congressional Down Syndrome Caucus (CDSC) was to increase awareness and to bring members together to focus on issues that directly impact those with Down syndrome in the United States.

Given the nature of the healthcare debate on Capitol Hill, it may come as no surprise that the CDSC has made Medicaid reform a primary focus in recent months. “What I see is that so much of the current system, as it pertains to those with disabilities, really keeps people in poverty and dependency,” said McMorris Rodgers. To qualify for the programs that those in the special needs community depend so heavily upon, they can have very few assets, because having them will prevent eligibility for many of the programs they may need to access later in life. The CDSC is seeking to put a safety net in place that, rather than oppressing the most vulnerable in our society, helps to empower them to become self-sufficient and to lead productive lives. McMorris Rodgers pointed out that there’s been huge progress over the last thirty years in the area of early intervention and education, but went on to express her desire to see more opportunities offered that will help those within the special needs community to live independently and hold down jobs - without the fear of the loss of benefits. She cited the example of Gail Williamson, the Executive Director of the Down Syndrome Association of Los Angeles. “Gail is actively trying to get those with Trisomy 21 into movies and television shows, but quite often they don’t even want to take the contract because it will increase their income for a short period of time, and jeopardize their ability to maintain their health insurance, or some other part of that safety net.”



In addition to focusing on Medicaid reform and employment for those with disabilities, the CDSC would also like to see an increase in college opportunities for those with Down syndrome. Programs such as the George Mason University Mason LIFE Program and the Mississippi State University ACCESS program allow students with disabilities the opportunity to further their education in a safe, controlled environment. This a wonderful strategy for helping those with special needs to learn to live independently and thrive. It also gives those students who feel called to work with the special needs community incredible hands-on experience as they study. Seeing more of these types of programs developed nationwide would be an enormous victory for the special needs community as a whole.

While these other areas of focus are important for the CDSC, the area of research seems to be their most crucial mission. “If we continue to research and come up with those new therapies or prescription drugs that make a difference, there will be some exciting and potential break-

throughs,” said McMorris Rodgers. “Rather than the focus being primarily on prenatal diagnosis, let’s look at putting more of that money towards figuring out how we can help individuals lead the most fulfilling lives possible.”

Since there are nearly 400,000 Americans who live with Down syndrome, this seems like a worthy goal. “In 2000,” according to Congresswoman McMorris Rogers’ web site, “Congress passed the *Children’s Health Act* which, among other things, authorized research for a number of conditions including juvenile diabetes, Fragile X, asthma, epilepsy, autism, and traumatic brain injuries. Down syndrome, however, was not included.” This hardly seems fair. According to Sara Weir, Policy Advisor for the NDSA, the legislation introduced by the CDSC in late July (H.R. 2696) “expands and intensifies Down syndrome programs of the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) to create an infrastructure of Down syndrome tools, including a Down syndrome contract registry, Down

syndrome research database, and Down syndrome biobank.” H.R. 2695 “will create at least six Down Syndrome Translational Research Centers of Excellence that provide an optimal venue and infrastructure translational research on Down syndrome.” Given the facts, I’m not sure how Congress could overlook legislation that so deeply affects such a large and special segment of our population. If you’d like to encourage your representative to cosponsor these bills, you may do so by calling the Capitol switchboard, 202-224-3121, and asking for your Representative.

Congresswoman Cathy McMorris Rodgers believes that life begins at conception, and that every child is a precious gift from God. Since giving birth to Cole in 2007, Grace Blossom Rodgers has joined the family, giving her a special place in history as the only Member of Congress to give birth twice while serving. What a joy to know that Americans with special needs have such a dedicated advocate in Washington, and that she and her fellow members on the Congressional Down Syndrome Caucus are doing all they can to see that children who are born with Down syndrome are given every opportunity to live a healthy and successful life.

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For more information on the mission and goals of the CDSC, visit <http://mcmorris.house.gov/index.cfm?sectionid=177&sectiontree=56,177>

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